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THE EFFECT OF LENGTH OF PARTICIPATION IN A PARENT  
SUPPORT GROUP ON REPORTED STRESS LEVELS  
OF PARENTS OF CHILDREN WITH AUTISM  
OR OTHER DEVELOPMENTAL DISORDERS

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Kimberly Sue McDonald

June 2001

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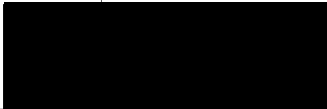
A Project  
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by  
Kimberly Sue McDonald

June 2001

Approved by:

  
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6-7-01  
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Donita Remington, Associate Director,  
University Center for  
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M.S.W. Research Coordinator

## ABSTRACT

This study examined the effects of a support group for parents of autistic children on the parents' reported stress levels. Subjects for the study were drawn from the support and information groups at the University Center for Developmental Disabilities at California State University, San Bernardino. Subjects completed a modified version of the Questionnaire on Resources and Stress - Friedrich Edition, which yielded a total stress score and four sub-scale scores. These scores were used to compare stress levels of parents that have attended the UCDD program for varying lengths of time. The trend was for the scores on most of the stress scales to steadily rise as the duration in program increased, however, an initial decrease in most stress scales was noted.



## ACKNOWLEDGMENTS

I would like to acknowledge the support and advice of Dr. Nancy Mary, Department of Social Work. She has not only assisted with guidance on this research project but has been instrumental in helping me continue in the program during personal hardships. I would also like to sincerely thank Donita Remington and Dr. Dwight Sweeney of the University Center for Developmental Disabilities for their support of my educational goals and assistance with this project.

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## CHAPTER ONE

### INTRODUCTION

#### Problem Statement

Raising a child is generally accepted to be stressful. Parenting a child with a developmental disability can add an additional burden to the already taxing job (Farber, 1959; Fotheringham & Creal, 1974; Holroyd & McArthur, 1976; Price-Bonham & Addison, 1978; Shapiro, 1989). Researchers have found that having a child with autism can be even more stressful than raising children with other developmental disabilities (Bristol & Schopler, 1984; Cutler & Kozloff, 1987; DeMyer, 1979; Cohen & Donnellan, 1987; Holroyd & McArthur, 1976; Schopler & Mesibov, 1984). This increased stress puts the parents of an autistic child at greater risk for negative outcomes such as: parent dissatisfaction, child abuse, low self-esteem, depression, and/or symptomology (Block, 1969; Cummings, Bayley, & Rie, 1966; DeMyer & Goldberg, 1983; Koeske & Koeske, 1990; Patterson, 1980; Marcus, 1984; Sullivan, 1979). These factors can influence the effectiveness of a parent in meeting the needs and specific challenges of their disabled child (Embry, 1980; Rosenberg, 1977). Due to this, intervention programs should include in their design components that lower the stress level of parents. One such component

that has been suggested as successful at lowering parental stress is parent support groups (Forstenzer & Curry, 1980; Fossen, 1983; Intagliata & Doyle, 1984; Reeves, 1979; Shapiro, 1989).

A high level of social support was found by Dyson (1996) to be a resilience factor for families reporting a high frequency of stress. This would suggest that a group providing support to families should help to decrease the stress experienced by them. Little research has been done on the effectiveness of such groups at lowering parental stress levels of families with a child who is developmentally disabled, particularly with the autistic population. This study sought to further the research in this area by examining the effects of a support group for parents of autistic children on the parents' reported stress levels. Subjects for the study were drawn from the parents who attend the support and information groups at the University Center for Developmental Disabilities at California State University, San Bernardino.

#### Problem Focus

Stress is a part of every day life. Some parent/child stress is considered necessary in order to

have an engaged relationship (Abidin, 1982). Chronic stress, however, has been shown to be detrimental to mental health, physical health, and family functioning (Block, 1969; Cummings, Bayley, & Rie, 1966; DeMyer & Goldberg, 1983; Koeske & Koeske, 1990; Patterson, 1980; Marcus, 1984; Seyle, 1956; Sullivan, 1979). As mentioned above, parents with autistic children may experience higher levels of stress than parents with typically developing children. Programs designed to aid these families in lowering their stress levels are necessary in order to promote healthy family environments and positive outcomes for their disabled children.

Research has been done which illustrates the effectiveness of social support on lowering stress (Bowlby, 19, Dyson, 1996). Several studies have shown that parent groups can serve as a social support for families with a disabled child (Forstenzer & Curry, 1980; Fossen, 1983; Intagliata & Doyle, 1984; Reeves, 1979). The support gained from attending these groups should serve to lower the stress levels experienced by participating families.



As social workers, it is important to know resources that are available which may benefit a family with a disabled child. The limited resources of government agencies and of families often limit the number of services a family with a disabled child may receive. It is important, therefore, that the service that is recommended be of the most benefit to the family at that time in their lives. Parent groups have been shown to be effective in lowering stress for their members and in providing much needed social support. The variables that make these programs successful needs to be researched. Better understanding of the variables involved would allow social workers to make referrals to groups that best match families' needs. Currently, little research has been done which addresses the length of time a parent attends a support group and its effect on stress level experienced by the parent. The purpose of this study was to investigate if the length of time a parent spent in a support group had an effect on the parent's reported stress level. A negative association was hypothesized between time in program and stress level. In this study stress level was defined as the total stress score from the Questionnaire for Resources and Stress - Friedrich Version (Friedrich, Greensberg & Crnic 1983).

## CHAPTER TWO

### LITERATURE REVIEW

Prolonged periods of high stress can have detrimental effects on an individual. Selye (1956) was a forerunner in the documentation of stress in relation to physical illness. Cardiovascular, gastrointestinal, and immune system problems, along with other physical complaints such as headaches and stomachaches are just a few problems that can occur (Selye, 1956; Haggarty, 1980). Chronically high levels of stress, often associated with parenting a child with a developmental disorder, has also been linked to an increase in emotional problems in parents such as: low self-esteem, depression, and parent dissatisfaction (Longres, 1995; Bradshaw & Lawton, 1978; Burden, 1980). These studies are an indication of the importance of lowering parental stress levels.

Much has been written regarding why some people experience less stress in similar situations. Social support has been found to be a major moderator (Baldwin, Brown, & Milan, 1995) and to serve as a buffer from stress (Bowlby, 1969, Crockenberg, 1981; Gill & Harris, 1991; Sarason, Levine, Basham, & Sarason, 1983). "Bowlby concluded that the availability of social support

bolsters the capacity to withstand and overcome frustrations and problem-solving challenges" (Sarason et. al., 1983). This "buffer effect" has been well documented in other fields of study. DeAraujo, Van Arsdel, Holmes, & Dudley (1973) found that asthmatic patients with good social supports needed lower levels of medication to produce clinical improvement than did asthmatics with fewer social supports. Much clinical evidence and anecdotal data (Sarason et. al., 1983) seem to back up the idea that positive relationships with significant others fosters self-reliance and the ability to persevere in the face of obstacles and distractions. Social support can be defined as information leading a person to believe that he is: (a) cared for and loved, (b) esteemed and valued, and (c) part of a network of mutual communication and obligation (Cobb, 1976 as presented in Gallagher, Beckman, & Cross; 1983). Bristol (1979) found that parents of other handicapped children could provide this support, in part. Fossen (1983) found that support is best if it comes from similar others. The author also states that parents will accept information when given by other parents that they had rejected by physicians or therapists. From these findings it can be assumed that groups, where parents share experiences and feelings with other parents who

have had similar experiences, should provide much needed support for participating families.

About the same time as Bowlby's research was making its mark, other researchers and practitioners began to turn their focus away from strictly targeting the identified client for treatment or study and began to recognize the importance of the family as a whole.

Historically, interventions for children with autism have focused simply on the identified child with the disability. Parents, especially mothers, were seen as the cause of their child's disability or at best of no use to its remedy. Increased knowledge about ecological influences and family dynamics encouraged the formation of programs designed to meet the needs of families instead of individuals. Services that increased positive family interactions by lowering parental stress with training, information, and support began to appear. Parents began to be seen as partners in treatment plans, instead of the cause of their children's handicaps, and were encouraged to participate in their children's educational, medical, and behavioral services.

According to Shapiro (1989) support groups are one of the most frequently recommended forms of intervention for parents of handicapped children by physicians, nurses, and other developmental specialists. There is

already some anecdotal evidence that participation in a support group has a beneficial effect on parental attitudes toward having a handicapped child (Forstenzer & Curry, 1980; Fossen, 1983; Intagliata & Doyle, 1984; Reeves, 1979). Shapiro (1989) found that mothers who participated in a support group were less depressed than those who did not; perceived themselves as less burdened by their child, and tended to engage in more problem-solving coping strategies with their child. Further, mothers who participated in a support group were found to appear more open and less anxious than mothers in the study who did not participate in a group. Also, participating mothers seemed to derive some benefit from discussing their problems with others and enjoyed helping to solve other people's problems. Participation in a support group was associated with diminished stress and lower depression.

Holroyd (1974) developed an instrument to measure a family's response to a handicapped family member. The instrument, The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS), was originally developed to identify families who required assistance. The QRS contains 15 sub-scales designed to assess different aspects of family stress. "It is difficult to measure stress in family systems or

to discern cause and effect because of interactions among child, parent, and family variables. The QRS scales provide an opportunity for phenotypic description of these interacting variables when one family member is severely ill or disabled. The scales reflect the response of an individual to potentially stressful events, which is desirable in research on stress" (Holroyd, 1988).

Holroyd in her summary of research using the QRS as a measure found that most of the QRS scales differentiate parents of retarded children from parents of normally developing children. Friedrich and Friedrich (1981) for example, compared mothers of children who were mentally retarded or who had motor problems with mothers of typically developing children. The mothers did not differ significantly in age, economic status, family size, or child's age. The QRS differentiated the two groups with the mothers of handicapped children scoring higher on twelve of the fifteen subscales. The three non-differentiating scales were 5(Lack of Social Support); 7(Pessimism); and 10(Financial Stressors).

Holroyd in her summary (1988) also found studies that demonstrated that the QRS could be used to discriminate between clinical groups. In one such study (Holroyd & McArthur, 1976) the QRS was given to mothers

of children who were diagnosed with either Autism, Down's Syndrome, or who were child psychiatry outpatients. The autistic group scored higher on all QRS scales except Financial Problems. Another study by Inanami, Nishi, & Ogura (1980) found similar results. The researchers compared mothers of four clinical populations: Mentally retarded, crippled, autistic, and blind. The mothers of autistic children tended to score higher on all scales. Rodrigue, Morgan, & Geffken (1992) found a similar effect for fathers of children with autism. In the study fathers of autistic children were found to experience greater stress than fathers of normally developing children. Stress in this study was inferred from scores on the Parenting Sense of Competence Scale (Gibaud-Wallston, & Wandersman, 1978) and The Ways of Coping Scale (Lazarus, & Folkman, 1984 modified by Felton, Revenson, & Hinrichsen, 1984). Friedrich, Greenberg, & Crnic (1983) found that overall mothers tend to have higher rates of stress than fathers on a short form of the QRS. These studies illustrate the high stress level for parents of autistic children and the QRS's ability to measure it.

In a study by Inanami et al. (1980) the gender of the child with a disability was looked at to see if this effected QRS scores. While differences were found in groups with mental retardation and among crippled

children, gender did not relate to QRS scores in the autism group.

Other variables that have been clearly demonstrated as having an effect on parents' reported stress level include marital status, marital satisfaction, and financial problems. Friedrich (1979) in a study looking at the predictors of mother's coping behavior in regards to their children, most of who had at least moderate mental retardation, found the mother's report of marital satisfaction had the greatest bearing on her reported capability in coping with her disabled child. Dyson (1996) found that single mothers with children who had learning disabilities scored higher on a revised version of the QRS. In a study by Baldwin, Brown, & Milan (1995) over 40% of the total stress measure on an adapted form of the QRS was accounted for by financial stressors when looking at caregiver stress with a population of children with ADHD. This indicates that any study looking at stress level in caregivers needs to take into account the influence of finances on parental stress levels.

The studies mentioned above looked at variables which may effect parents' reported stress levels on the QRS. The researchers were concerned with parent and child variables. Little research has been done on what variables of the support group itself influence its



effectiveness with the parents of autistic children. Quantitative evidence needs to be established that can guide program developers in creating new programs or improve established programs. This study looked at one such variable - the length of time in program and its relationship to reported stress levels for parents of autistic children. The parent/child variables that have been found in past research to have an effect on support group success were also looked at (financial stressors, marital status, gender, number of children in the home, child's diagnosis and number of social supports). The variables were examined this time, however, in relationship to time in a support group.

## CHAPTER THREE

### METHODOLOGY

#### Study Design

Some stress in life is necessary for normal functioning. Chronically high stress levels, however, can be harmful to physical health and mental functioning. Parents who have a child with a disability generally experience greater stress than families without disabled children. Programs have been established recently to aid these parents in dealing with the added stressors. The University Center for Developmental Disabilities (UCDD) is one such program that attempts to supply parents with the information and support they need in an effort to lower their stress level and cope better with raising a disabled child. This study will attempt to quantify the effects of the UCDD parent group on parents' reported stress levels.

This research project is an explanatory study. Following in the traditional empirical positivist perspective, it looked at the effects of length of participation in the UCDD parent information and support group on relieving parental stress. It used a cross-sectional comparison group post-test only design. A questionnaire was utilized to gather data regarding

parental stress level and a demographics survey was used to obtain information regarding length of time in program and information on other pertinent variables (gender, income, marital status, child's diagnosis, number of children in the home, and number of social supports utilized regularly).

It was predicted that the length of time a parent spent in the UCDD parent information and support group would have an effect on the parent's reported stress level. More precisely, a negative association was hypothesized between time in program and stress level as measured by the total stress score obtained using a questionnaire.

A methodological concern with this study was that stress is such a complex issue that extraneous variables may interfere with the ability of the chosen stress measure to perceive a difference due to length of time in program. Parents may truly experience a positive effect from a support group related to stress, but be so overwhelmed with other issues that no difference is found.

#### Sampling

Subjects were drawn from the UCDD parent information and support group. At the time of the study UCDD had a

client list of 92 developmentally disabled children and their families. The children are referred to UCDD from the Inland Regional Center with a diagnosis of a developmental disability, usually Autism. Parents are referred to the UCDD program continuously throughout the year and are placed in established groups. This means that parents in each group will range in the amount of time they have spent in the program from just starting to over two years.

All attending parents or guardians from each family were invited to participate regardless of the family dynamics: i.e. single, married, remarried (with one or both sets of parents attending), etc. Families in the UCDD pre-group, consisting of parents waiting to begin the full program who attend a bimonthly information group with out their children attending the program, served as a control group. Only parents who participate in the support group were asked to be involved in the study. Spouses and significant others who did not regularly attend the weekly sessions were not asked to participate. This is due to the desire to strictly measure the effect of the support and information group on parental stress level and not the subsequent effect on other non-participating family members.

## Data Collection and Instruments

Data was obtained in this study by a research questionnaire (appendix A) requesting basic demographic information including age, gender, marital status, child's IRC diagnosis, and family income. In addition, the questionnaire asked parents to fill in information about the independent variable of greatest interest to this study: "length of time in program".

Stress level of parents was measured using a modified version of the Questionnaire on Resources and Stress-Friedrich Edition (QRS-F; Friedrich et al., 1983). The QRS-F is a shorter version of the Questionnaire on Resources and Stress (QRS; Holroyd, 1974). The QRS is a 285-item true-false questionnaire designed specifically to measure stress in families with a disabled member. Scores are obtained on 15 distinct scales that can be summed to yield a total stress score. In an effort to establish a shorter and psychometrically stronger measure, Friedrich, Greenberg, & Crnic (1983) analyzed data from 289 QRS's. They found that 52 items emerged as most reliable and thus formed QRS-F, a shorter version of the QRS.

The Friedrich version has 4 sub-scales. The first is the Parent and Family Problems scale which consists of 20 items that assess the respondent's perception of

problems for themselves, other family members, or the family as a whole. Sample questions include "I get upset with the way my life is going," and "Our family agrees on important matters."

The second scale, Pessimism, consists of 11 items that attempts to measure the immediate and future pessimism about the disable child's prospects of achieving self-sufficiency. Sample items include "\_\_\_\_\_ will always be a problem to us," and "\_\_\_\_\_ does not do as much as he/she should be able to do."

Child Characteristics is the third scale and it consists of 15 items. This scale involves the respondent's perception of the specific behavioral or attitudinal difficulties presented by the disabled child. Sample items include "\_\_\_\_\_ doesn't communicate with others of his/her age group," and "Sometimes I avoid taking \_\_\_\_\_ out in public."

The final scale is the Physical Incapacitation scale and it consists of six items that involve the respondent's perceptions of limitations in the disabled child's physical abilities. Sample questions include "\_\_\_\_\_ can feed him/herself," and "\_\_\_\_\_ is able to take part in games or sports."

The correlation between the total scores of the QRS and this shorter form is 0.997. In a study by Scott,

Sexton, & Thompson (1989) the QRS-F was found to "have reasonable psychometric integrity, as indicated by several reliability, factor structure, and construct validity analyses."

In order to create a more sensitive instrument, the present study used a modified version of the QRS-F. The true-false format was changed to a four-point Likert scale format. This scale arranged answers on a one to four range, with one representing "strongly agree" and four representing "strongly disagree." This allowed for more subtle differences between the "time in program" groups to emerge. The total stress score (dependent variable) was examined in relation to time the parent has spent in the UCDD parent information and support group (independent variable). In this study it was hypothesized that, taken together, the demographic questionnaire with its "time in program" inquiry and the modified QRS-F would demonstrate a negative correlation: a higher total modified QRS-F score with lower time in program duration.

#### Procedure

Questionnaires were handed out to parents in each of the UCDD parent groups by this researcher. The UCDD program has a total of nine such groups, which meet once

weekly, Monday through Thursday evening from 6:00 - 8:30 p.m. or Saturday mornings from 9:00 - 11:30 a.m. Monday through Thursday evenings two such groups run in different locations. In addition to these groups, a Pre-group, composed of parents whose child is on the UCDD waiting list, meets twice a month on the first and third Tuesday from 6:30 to 8:30 p.m. The forms were handed out approximately one hour after the sessions had begun in order to give time for late arrivals, but to ensure enough time was left for the completion of the forms.

The questionnaires were handed out over a two-week period allowing for this researcher to administer and collect all the forms in an effort to diminish any variance in how it was presented. The QRS-F modified form was given to parents along with a pencil. The instructions were read aloud by me as they read along silently. The respondents answered each question as it applied to themselves, their family, or their child. Questions asked by respondents were redirected back to them with gentle prompting "Answer in the best way that you can." The QRS-F was completed and returned to this researcher during the normally scheduled parent group session. This was done in an effort to generate a greater response rate than would be expected if forms were taken home by the parents and completed. No "make-



up" questionnaires were handed out in order to collect forms from parents who may be absent from the UCDD parents groups on the days they are administered. This kept the time needed for test administration and collection at two weeks.

### Protection of Human Subjects

Identifying information, for example name or address, were not collected either on the QRS or demographics forms. Instead, numbers were placed on the top of each form which parents could write down and keep for future identification of their scores in comparison with other UCDD families. Also, in an effort to protect parents' confidentiality, as few individuals as possible were allowed access to the raw data. Persons identified at this time who may have access to this data would include myself, my MSW research supervisor, Donita Remington (Associate Director for UCDD), and Dr. Dwight Sweeney (Director, UCDD).

### Data Analysis

The scores for the QRS-F modified were tabulated as follows: 1-point for each item answered "agree" or "disagree" and 2-points for each item answered "strongly agree" or "strongly disagree" if in the direction indicated by the scoring templates (see attached) -1 or -

2, respectively, if not. After tabulating the score for each question, the scores were summed for a "total stress score." Following calculation and inspection of frequency distributions Pearson correlations were computed to examine the relationship between the length of time in program with the QRS-F modified total and subscale scores. Chi-squared and t-test analysis were also done to examine the effects of the independent variables on the stress scores.

## CHAPTER FOUR

### FINDINGS AND RESULTS

#### Participants' Characteristics

Subjects consisted of 69 family members of clients who attended the UCDD support groups during the administration of the surveys. With the exception of one, all family members in attendance during the administration of the surveys participated for a total of 68 returned questionnaires. Due to the fact that multiple family members may have been present, the number of families actually represented in the population is unknown.

Participants consisted of 48 females (70.6%) and 20 males (29.4%). A majority of respondents (91.2%) were the natural parent of a child attending the UCDD program. Other respondents were stepparents (4.4%) or grandparents (4.4%). Most subjects were married (76.5%), 7 were divorced (10.3%), 3 were single (4.4%), and 6 reported being currently separated (8.8%). The average income was between \$35,000 and \$44,999. Autism was the most frequent diagnosis experienced by the children of the respondents. Ninety five point six percent stated this as their child's diagnosis or as part of their child's diagnosis. Twenty two percent of the children

experienced autism and mental retardation, while 7% experienced autism and either cerebral palsy (2.9%) or seizure disorder (4.4%). Only one child had a diagnosis of mental retardation alone (1.4%) and two children had other diagnosis (Fragile X or Retts Syndrome). In summary, Chart 1 below illustrates the percentages of diagnosis experienced by clients with autism as at least part of their diagnosis.

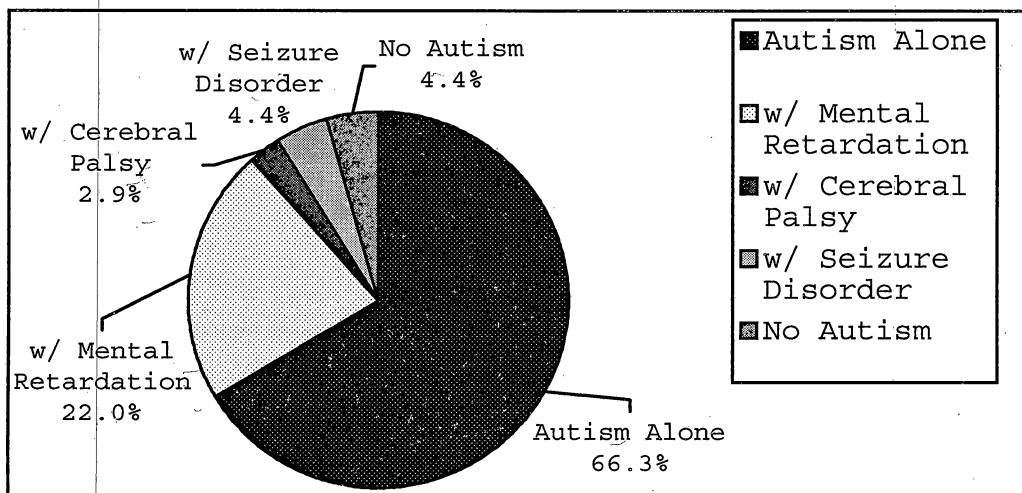


Figure 1. Diagnosis of Clients

#### Length of Time in Program and Parental Stress Levels

Subjects were categorized into one of six groups corresponding with how long they have participated in the UCDD program. Subjects were placed in the pre-group category if they had not started the full program or in

one of five other groupings depending on the number of months in the program. In Table 1, the number of subjects in each group is displayed as well as the mean stress scores for the QRS total stress score (TSS) as well as the four sub-scales: Parent and Family Problems (PFPROB), Pessimism (PESS), Child Characteristics (CHILDCH), and Physical Incapacitation (PHYS).

Table 1. Mean Stress Scores

Time in Program		TSS	PFPROB	PESS	CHILDCH	PHYS
Pre-Group	Mean	133.80	46.60	31.40	44.20	11.60
	N	5	5	5	5	5
1-3 Months	Mean	120.73	45.09	27.55	35.73	12.36
	N	11	11	11	11	11
4-6 Months	Mean	124.67	44.83	30.00	38.00	11.83
	N	6	6	6	6	6
7-12 Months	Mean	129.20	46.67	30.00	39.73	12.80
	N	15	15	15	15	15
13-18 Months	Mean	130.33	48.44	29.56	39.11	13.22
	N	9	9	9	9	9
19-24 Months	Mean	139.50	51.60	33.30	41.50	13.10
	N	10	10	10	10	10
More than 24 Months	Mean	139.58	51.92	31.83	43.25	12.58
	N	12	12	12	12	12
Total	Mean	131.26	48.13	30.46	40.07	12.62
	N	68	68	68	68	68

A positive correlation was found between time in program and the total stress score as well as with all of the sub-scales with the exception of the physical characteristics scale, which tended to remain stable across groups. However, a negative correlation was found

between time in the UCDD program and the QRS total stress score between the pre-group and subjects in the program one to three months. All of the sub-scales showed a decrease in scores between these groups as well, except for the physical scale, which as mentioned above, tended to remain stable. The decrease was significantly lower for the pessimistic and child characteristics scales ( $t=2.245$ ,  $df=14$ ,  $p=.041$ ;  $t=2.236$ ,  $df=14$ ,  $p=.042$ , respectively). Though not significant, the parent and family problem scale also had a dramatic reduction between the scores obtained from the pre-group and the group in the program one to three months. This would seem to indicate that the UCDD program has an immediate effect at lowering parental stress levels upon entry into the program. The initial decrease as well as the subsequent rise in scores is illustrated in Chart 2 and 3 below.

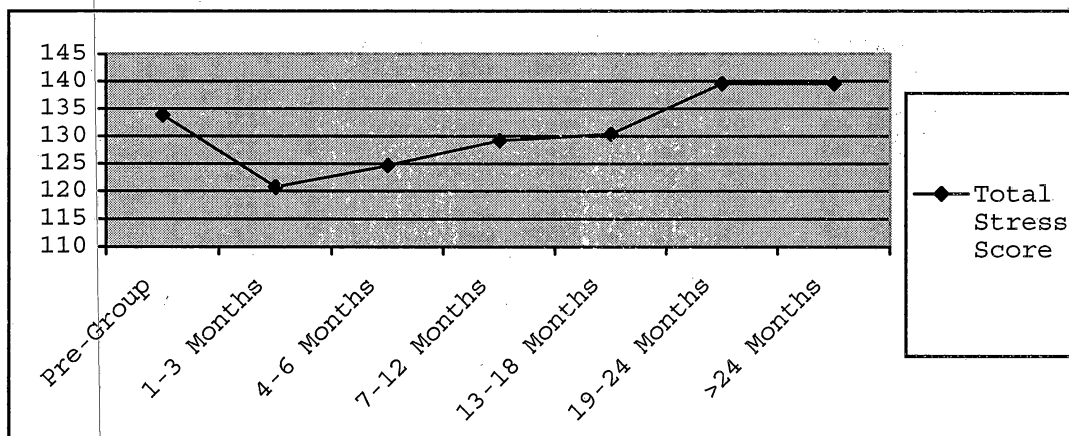


Figure 2. Total Stress Score Means

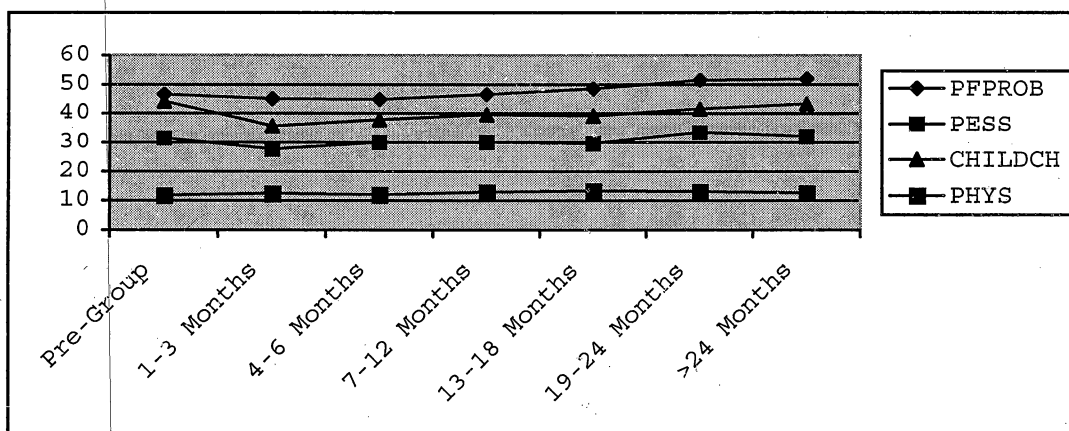


Figure 3. Means of Sub-Scales

### Questionnaire on Resources and Stress Scores and Independent Variables

T-tests and chi-square analyses were conducted to examine the effects of gender, marital status, number of children in the home, family income, and reported social supports on the QRS scores. No significant differences between the groups regarding these variables were found. A positive correlation was found between the QRS total stress score and the subjective stress level ( $r=.401$ ,  $p<.01$ ) as reported by participants in the demographic survey. This finding also held true for the sub-scales, excluding the physical incapacitation scale, (PFPROB  $r=.430$ ,  $p<.01$ ; PESS  $r=.337$ ,  $p<.01$ ; CHILDC  $r=.212$ ,  $p<.05$ ). A mean subjective stress score of 6.69 and a mode of 8 on a scale from one to ten indicates that most of the subjects viewed themselves as experiencing a high level of stress.



## CHAPTER FIVE

### DISCUSSION

Overall, the data from the present study did not demonstrate support for the central expectations, but provided unanticipated results. Parental stress levels, as measured by the QRS and its sub-scales, tended to rise as length of time in program increased. The QRS total stress score as well as three of its four sub-scales (PFPROB, PESS, and CHILCH) demonstrated this effect. The Physical Incapacitation scale was the only measure that did not increase significantly. This may be due to the fact that physical disabilities tend to remain stable, which causes a consistent stress level to be experienced by the parents.

There was an initial significant drop in QRS scores for the total stress score as well as three of the four sub-scales for parents in the program for one to three months as compared to the pre-group. This would seem to indicate that the UCDD program has an immediate effect at lowering parental stress levels upon entry into the program. Then, as noted above, the scores tended to rise. There may be several possible explanations for

this rise in stress. First, it is possible that the results were due to experimental procedures or, perhaps, they reflect an actual difference between the groups; i.e. the later groups contained individuals experiencing more stress than the newer groups. It is also possible that the parents truly experienced more stress as the time in program increased. The most plausible explanation, however, may be that the increase of stress scores over time is due to parent attrition as opposed to an overall stress level gain. After reaping the benefits of the program and gaining the skills, knowledge, and support they need, many parents may exit the program leaving behind a group of parents that are experiencing severe levels of stress and are in need of continued services and support. This explanation is further supported by the fact that after 18 months in the program, parents must demonstrate a substantial need and petition to remain in the program, suggesting that they are experiencing a high enough level of stress to put forth a substantial effort. Examination of stress levels of parents exiting the UCDD program would help to clarify this issue.

## Implications for Practice

Overall, this study's findings have several practical implications. The overall high stress levels demonstrated by both the QRS scores and the subjective stress scores of the participants demonstrate a need for support groups to include stress management as part of their program design. The results from the QRS sub-scales would also indicate that group counselors should design interventions that target those areas of stress that have the greatest impact on the total stress level experienced by parents. Results of this study would indicate that interventions designed around the three sub-scales with the highest increase should be the main focus.

The results of this study would also indicate that agencies need to lengthen the duration of their programs to accommodate parents that are experiencing higher levels of stress. Such an approach is inconsistent with the current practice of many programs, which tend to have an artificial limit to their length of services.

### Limitations of This Study and Implications for Future Research

It should be emphasized that many of the current findings are correlational and therefore inconclusive in respect to whether length of time in program truly affects stress level. Research involving longitudinal designs rather than cross-sectional designs may permit a better understanding of the causal networks surrounding parental stress and support groups.

Also noteworthy was that no specific between-groups differences emerged in regards to any of the demographic variables. This lack of significant differences contrast with previous research. It is possible that the differences were not detected due to experimental procedures. Perhaps a more stringent protocol would have yielded different results.

Another explanation for lack of significant differences between groups could be that the variables affecting stress are so numerous and convoluted that the demographic measure used in this study was simply incapable of finding significant differences.

While this study examined parental support in connection to several demographic variables, future

research should focus on important variables not included in this study. These variables may include religion, ethnicity, educational level, etc.

In conclusion, the present research only begins to explore potentially important factors affecting parental stress levels. Further research will be needed to clarify the issues raised by this study.

APPENDIX A  
DEMOGRAPHIC SURVEY



**CALIFORNIA STATE UNIVERSITY  
SAN BERNARDINO**

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**University Center for Developmental Disabilities**

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**How long have you been in the full UCDD program?**

\_\_\_\_\_ months, \_\_\_\_\_ years

**Your gender:**

☐ Male ☐ Female

**What is your relationship to the child that attends the UCDD program?**

☐ Natural mother ☐ Natural father  
☐ Stepmother ☐ Stepfather  
☐ Adoptive parent ☐ Grandparent  
☐ Other relative ☐ Other - please specify \_\_\_\_\_

**Your marital status:**

☐ Single (never married)  
☐ Living with partner or spouse  
☐ Divorced  
☐ Separated from spouse or partner  
☐ Widowed

**How is your spouse or partner related to your child in the UCDD program?**

☐ No spouse or partner  
☐ Natural mother/father  
☐ Stepparent  
☐ Adoptive parent ☐ Other, please specify \_\_\_\_\_

**What is your total family income?**

☐ Below \$15,000  
☐ \$15,000 - \$24,999 ☐ \$25,000 - \$34,999  
☐ \$35,000 - \$44,999 ☐ \$45,000 - \$54,999  
☐ \$55,000 - \$64,999 ☐ above \$65,000

**How much supervision does your child attending the UCDD program need?**

- ☐ Little or no supervision
- ☐ Supervision some of the time
- ☐ Supervision most of the time
- ☐ Constant supervision

**What is the diagnosis of your child attending the UCDD program?  
Check all that apply**

- ☐ Mental Retardation
- ☐ Autism
- ☐ Seizure Disorder
- ☐ Cerebral Palsy
- ☐ Other \_\_\_\_\_

**If your child is diagnosed with Mental Retardation what is the severity?**

- ☐ Mild
- ☐ Moderate
- ☐ Severe

**How many children are living in your home? \_\_\_\_\_**

**What types of social support do you receive on a regular basis?**

- ☐ Tangible support from family (e.g. money, baby-sitting).
- ☐ Emotional support from family
- ☐ Tangible support from friends (e.g. money, baby-sitting).
- ☐ Parent groups other than UCDD
- ☐ Emotional support from friends
- ☐ Professional groups
- ☐ Other, please specify \_\_\_\_\_

**In your opinion what is your average daily stress level.  
Circle 1 for low or no stress, 5 for moderate, and 10 for high  
or extreme stress.**

— 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 —>



APPENDIX B  
QUESTIONNAIRE ON RESOURCES AND  
STRESS - MODIFIED FRIEDRICH  
EDITION

Please answer the following questions by circling the response which most closely applies: SD (strongly disagree), D (Disagree), A (Agree), or SA (Strongly Agree).

- |  |           |
|--|-----------|
| 1. My child doesn't communicate with others of his/her age group.  | SD D A SA |
| 2. Other members of the family have to do without things because of my child.  | SD D A SA |
| 3. Our family agrees on important matter.  | SD D A SA |
| 4. I worry about what will happen to my child when I can no longer take care of him/her.   | SD D A SA |
| 5. The constant demands for care for my child limit growth and development of someone else in our family.                                | SD D A SA |
| 6. My child is limited in the kind of work he/she can do to make a living.   | SD D A SA |
| 7. I have accepted the fact that my child might have to live out his/her life in some special setting (e.g., institution or group home). | SD D A SA |
| 8. My child can feed himself/herself.  | SD D A SA |
| 9. I have given up things I have really wanted to do in order to care for my child.  | SD D A SA |
| 10. My child is able to fit into the family social group.  | SD D A SA |
| 11. Sometimes I avoid taking my child out in public.   | SD D A SA |
| 12. In the future, our family's social life will suffer because of increased responsibilities and financial stress                       | SD D A SA |
| 13. It bothers me that my child will always be this way.   | SD D A SA |
| 14. I feel tense whenever I take my child out in public.   | SD D A SA |
| 15. I can go visit with friends whenever I want.   | SD D A SA |
| 16. Taking my child on a vacation spoils pleasure for the whole family.  | SD D A SA |
| 17. My child knows his/her own address.  | SD D A SA |
| 18. The family does as many things together now as we ever did.  | SD D A SA |
| 19. My child is aware who he/she is.   | SD D A SA |
| 20. I get upset with the way my life is going.   | SD D A SA |
| 21. Sometimes I feel very embarrassed because of my child.   | SD D A SA |
| 22. My child doesn't do as much as he/she should be able to do.  | SD D A SA |
| 23. It is difficult to communicate with my child because he/she has difficulty understanding what is being said to him/her.              | SD D A SA |
| 24. There are many places where we can enjoy ourselves as a family when my child comes along.  | SD D A SA |
| 25. My child is over-protected.  | SD D A SA |
| 26. My child is able to take part in games or sports.  | SD D A SA |
| 27. My child has too much time on his/her hands.   | SD D A SA |
| 28. I am disappointed that my child does not lead a normal life.   | SD D A SA |
| 29. Time drags for my child, especially free time.   | SD D A SA |
| 30. My child can't pay attention very long.  | SD D A SA |
| 31. It is easy for me to relax.  | SD D A SA |
| 32. I worry about what will be done with my child when he/she gets older.  | SD D A SA |
| 33. I get almost too tired to enjoy myself.  | SD D A SA |
| 34. One of the things I appreciate about my child is his/her confidence.   | SD D A SA |
| 35. There is a lot of anger and resentment in our family.  | SD D A SA |
| 36. My child is able to go to the bathroom alone.  | SD D A SA |
| 37. My child cannot remember what he/she says from one moment to the next.   | SD D A SA |
| 38. My child can ride a bus.   | SD D A SA |
| 39. It is easy to communicate with my child.   | SD D A SA |
| 40. The constant demands to care for my child limit my growth and development.   | SD D A SA |
| 41. My child accepts himself/herself as a person.  | SD D A SA |
| 42. I feel sad when I think of my child.   | SD D A SA |
| 43. I often worry about what will happen to my child when I no longer can take care of him/her.  | SD D A SA |
| 44. People can't understand what my child tries to say.  | SD D A SA |
| 45. Caring for my child puts a strain on me.   | SD D A SA |
| 46. Members of our family get to do the same kinds of things other families do.  | SD D A SA |
| 47. My child will always be a problem to us.   | SD D A SA |
| 48. My child is able to express his/her feelings to others.  | SD D A SA |
| 49. My child has to use a bedpan or a diaper.  | SD D A SA |
| 50. I rarely feel blue.  | SD D A SA |
| 51. I am worried much of the time.   | SD D A SA |
| 52. My child can walk without help.  | SD D A SA |

APPENDIX C  
INFORMED CONSENT

### **Informed Consent**

I am volunteering to participate as a subject in this study. Kimberly McDonald, an MSW student under the supervision of Dr. Nancy Mary of the Dept. of Social Work at CSUSB (909) 880-5560, is conducting this study. The Social Work Department Review Board at CSUSB has approved this research project.

I understand that the purpose of this study is to explore parental stress levels for families that have a child with a developmental disorder. I understand that I will be asked to complete a paper and pencil questionnaire, which will include questions about my family and my feelings toward my child with a disability. The questionnaire will take approximately 15 minutes to complete. I will also be asked to answer several demographic questions.

I understand that my name will not be included on the survey itself and that **my anonymity will be maintained at all times**. I also understand that my participation in this study is voluntary, that all my questions will be answered, that I may refuse to answer any questions at any time, and that I may withdraw from the study at any time without penalty or prejudice. My choice to participate in this study will in no way affect my UCDD status.

By placing a mark in the space provided below, I acknowledge that I have been informed of, and understand, the nature and purpose of this study, and I freely consent to participate. By this mark I further acknowledge that I am at least 18 years of age.

**Please give your consent to participate by placing an "X" below:**

**Date:** \_\_\_\_\_

APPENDIX D  
DEBRIEFING STATEMENT

### **Debriefing Statement**

Thank you for participating in this study. The purpose of this study was to examine the effects of the UCDD parent group on reported parental stress level. More specifically, the relationships between the amount of time parents have participated in the UCDD program and their reported stress level. It is hoped that the results of this study will contribute to a better understanding of the effects of UCDD's support and information groups on parental stress levels.

The research data will be collected through the questionnaires you have completed. All data collected will be kept confidential and anonymous. Please feel free to express any feelings you may have about participating in this project. Your group counselor will be available to discuss any concerns or issues that you may have.

The results of this study will be available in the CSUSB Pfau Library and in the UCDD Resource Library by the summer of 2001. If you have any questions or concerns regarding this research project you may contact Kimberly McDonald through Dr. Nancy Mary at the CSUSB Department of Social Work at (909) 880-5501.

Thank you again for your participation in this research project.

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